



## **MASSACHUSETTS CENTER FOR BIRTH DEFECTS RESEARCH AND PREVENTION MASSACHUSETTS DEPARTMENT OF PUBLIC HEALTH**

### **Public Health Resources Available for Families Affected with a Birth Defect**

Planning for children with special health care needs is essential to support affected infants and families. Coordination of birth defects data with maternal and child health programs helps to ensure services for identified children and to provide population-based information to direct program planning and prevention strategies (Walker 2000).

The Massachusetts Department of Public Health serves mothers and children with special health care needs through a variety of programs and services. The Department also supports a number of initiatives and activities designed to prevent birth defects and improve overall pregnancy outcomes of mothers and infants.

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Massachusetts Department of Public Health  
250 Washington Street  
Boston, Massachusetts 02108  
(617) 624-6000  
[www.state.ma.us/dph/](http://www.state.ma.us/dph/)

### **Child Health Diary**

The Child Health Diary is a health education and outreach tool currently available in English, Spanish, and Portuguese. The Child Health Diary, or Growing Up Healthy / Creciendo Sano / Crescer Saudável provides health, safety, child development, and parenting information. It is easy for parents to use with pockets for the official immunization record and other documents as well as a resource list of family support services. Growing Up Healthy is distributed at all birthing hospitals, WIC programs, home visiting programs, adoption agencies, and pediatric practices. Parents may obtain individual copies by calling the Massachusetts Health Promotion Clearinghouse at (800)-952-6637.

### **Children's Medical Security Plan (CMSP)**

A health insurance program that provides children and adolescents with access to primary care and preventive services. Any child age 18 or younger who lives in Massachusetts, is currently uninsured for primary or preventive health care, and is not eligible for primary or preventive health care coverage through [MassHealth](#) is eligible for coverage under CMSP. For further information call (800)-531-2229 or check the web site at [http://www.state.ma.us/dma/masshealthinfo/applmemb\\_IDX.htm](http://www.state.ma.us/dma/masshealthinfo/applmemb_IDX.htm).

### **Early Intervention**

Early intervention is an integrated developmental service available to the families of children, between birth and three years of age, for whom there are developmental concerns due to identified disabilities, or whose typical development is at risk due to certain birth or environmental circumstances. Early intervention programs provide comprehensive, integrated services, utilizing a family-centered approach to facilitate the developmental progress of eligible children. Early intervention services are designed to meet the developmental needs of each child and the needs of the family related to enhancing the child's development. Services are selected in collaboration with families and focus on the concerns, priorities and available resources of the family in relation to the child's needs; parent(s) are involved in the process of assessment, development of the Individualized Family Service Plan (IFSP) and on-going programming. Staff disciplines on individual teams may include speech, occupational and physical therapists, developmental educators, social workers, psychologists and nurses. In addition, early intervention programs may contract with consultants in areas such as nutrition, adaptive equipment, and behavior management. For additional information on early intervention services, please contact the Massachusetts Department of Public Health, Early Intervention Services at 617-624-5070 or call Family TIES, the statewide information, resource, referral and support network for families. Family TIES can be reached at 1-800-905-TIES or 8437. For further information check the web site at <http://www.state.ma.us/dph/shcn/ei.htm>.

### **Family and Community Support**

Family and Community Support programs promote the well being of children with special health care needs and their families. Experienced staff work with families to ensure access to appropriate community based services for children with complicated health needs and collaborate with educational, social service and medical providers to minimize fragmentation in service delivery and advocate for the development of comprehensive community based systems of care for children with complicated health needs. Information, referral, and technical assistance are provided to parents and providers as needed. Service coordination is provided to any family whose child has a disabling condition, chronic illness, or is dependent upon medical technology and is experiencing difficulty in obtaining or maintaining services. A care coordinator and family work together to develop and implement an Individualized Family Service Plan to ensure timely resolution of family need. For further information call (617)-624-5070 or (800)-882-1435. The web site is located at <http://www.state.ma.us/dph/shcn/famsupp.htm>

### **Family TIES**

This program provides statewide parent-to-parent support and an information and referral network for families and providers involved in the care of children with special needs. Provides a toll free in-state phone line (800)-905-TIES (8437), an annual conference, a Parent Speaker's Bureau and serves as the central directory for Early Intervention services. A website ([www.massfamilyties.org](http://www.massfamilyties.org)) links parents and providers with up to date information on services and supports.

### **FIRSTLink**

FIRSTLink is MDPH's newborn screening and community referral system. FIRSTLink identifies newborns and their families with conditions that can contribute to poor health and development. Participation in FIRSTLink is completely voluntary and parents may change their mind at any time. FIRSTLink home visitors meet with the parents to conduct a family needs assessment to identify services and assure that linkages to primary health care and other critical services are in place for the infant and other members of the family. For further information call (617) 624-6060 or check the web site <http://www.state.ma.us/dph/flink.htm>.

### **FIRSTSteps**

*FIRSTSteps* provides comprehensive, prevention-oriented, voluntary home visiting services for at-risk families with children from pregnancy through age three, along with a range of complementary services such as parent groups and other activities to build competencies and social support systems for families. Core service elements include parenting

education and support, infant/toddler developmental screening, health assessment and monitoring, health promotion and anticipatory guidance, and service coordination, delivered by a multidisciplinary team of professionals and paraprofessionals. *FIRSTSteps* is available in selected cities/towns. For further information call (617) 624-5589.

### **Folic Acid Campaign**

MDPH is currently conducting a major health promotion campaign to prevent the birth of babies with spina bifida and other neural tube defects by ensuring that all women of reproductive age get adequate amounts of folic acid in their diet. The Folic Acid Campaign coordinates MDPH programs and public/private agencies to provide a multimedia approach to raising awareness of the importance of adequate intake of folic acid throughout the life span. Intake of 0.4 mg daily of folic acid has also been shown to reduce the risk of certain birth defects and to reduce the risk of heart disease and some forms of cancer in adults. For further information call (617)-624-5070 or (800)- 882-1435.

### **Growth and Nutrition Program**

The Growth and Nutrition Program makes expert services available to children and their families to ensure that compromised nutrition does not impair the health and development of children in the Commonwealth. Services of the Growth and Nutrition Program include home visits, out-patient and, when necessary, in-patient care. Services are open to any child within the Commonwealth whose growth pattern poses a concern to parents or providers. Multidisciplinary teams with a physician, a nutritionist, a nurse, a social worker, and a psychologist or care coordinator offer children with growth delays evaluation and treatment through referrals from primary care providers, hospitals, and community-based agencies, including nutrition programs. For further information call (617) 624-5070 or (800) 882-1435. More information can be found at <http://www.state.ma.us/dph/shcn/gnc.htm>.

### **Healthy Families**

The Healthy Families program provides comprehensive, prevention-oriented, voluntary home visiting services for all first-time parents under 21, beginning in pregnancy and continuing until the child reaches age three. The primary goals of the services are to assist young parents to 1) develop effective parenting skills to ensure the optimal health and development of their children; 2) prevent repeat teen pregnancies; 3) attain maximum educational achievement; 4) develop the capability to support themselves and their children; and 5) have healthy birth outcomes. Programs include a broad range of home visiting and center-based services. For further information contact the Massachusetts Children's Trust Fund at (617)-727-8957

### **Hearing Screening Program for Infants and Toddlers**

The Hearing Evaluation Program for Infants and Toddlers is dedicated to the early identification of hearing loss in infants and young children. When babies with hearing loss are identified early, intervention can have a dramatic, positive impact on speech, language, and overall development. Each birth hospital and birth center in the state is required to have a program to ensure that every baby is hearing screened before going home. Babies who do not pass or miss a hearing screening are referred to audiological diagnostic centers approved by the Department of Public Health. This program was established because early identification of hearing loss along with early intervention services has been proven to result in improved language development. This early start in language development has implications for reducing the need for extensive special educational support. For further information call (800)-882-1435. The web site is located at <http://www.state.ma.us/dph/shcn/hearing.htm>.

### **Immunization Program**

The primary goal of the Immunization Program is the complete and timely vaccination of all children in the Commonwealth to prevent the occurrence of vaccine-preventable diseases. The Immunization Program universally provides all recommended childhood vaccines to public and private providers and to school-based programs. Through its educational activities and its collaborations with public and private agencies, the Program is providing families and communities with the resources and tools necessary to identify local needs and ensure the delivery of immunizations to all children. For further information on the Department of Public Health Immunization Program call (888)-658-2850 or visit the Department of Public Health website at <http://www.state.ma.us/dph>.

### **Massachusetts Genetics Program (MGP)**

MGP provides the public and professionals with information concerning developments in genetics, as well as access to high quality, family-centered genetic counseling, testing, treatment, and support services. The Genetics Program maintains an up- to- date base of information on genetic conditions, tests and treatments. This program is responsible for presenting genetic education and training programs to consumers and to the staff of agencies serving consumers with genetic conditions or concerns. For further information call (617) 624-5070 or (800) 882-1435. The genetics program web site is

<http://www.state.ma.us/dph/shcn/genes.htm>

### **New England Newborn Screening Program**

The New England Newborn Screening Program is a comprehensive public health screening program for newborns, providing service for five New England states. The program provides high quality, timely, low-cost laboratory screening, clinical follow-up and research to prevent or minimize the effects of disorders that can lead to death, mental retardation and life-compromising conditions in newborns. In the rare cases when a disorder is found, early diagnosis and treatment can usually prevent the problems associated with these disorders. Newborn screening tests provide an early opportunity to detect certain disorders before symptoms appear. In Massachusetts, there are ten treatable diseases that are included in Routine Newborn Screening. Under Massachusetts law, it is a requirement that all babies born in Massachusetts be screened for signs of these ten diseases unless parents object on the basis of religious beliefs. Massachusetts is offering newborn screening for an additional twenty disorders at no extra costs or additional blood samples. The New England Regional Newborn Screening information can be found at <http://www.umassmed.edu/nbs/> or call (617)-983-6300.

### **Perinatal and Pediatric Primary Care Programs**

Perinatal and Pediatric Primary Care Programs use a comprehensive, community-based system of care to provide accessible, affordable, and culturally appropriate services to low income pregnant and postpartum women, children and adolescents at-risk for poor birth, health, and developmental outcomes. Perinatal and Pediatric Primary Care Programs are an integral part of a coordinated, community-based strategy which recognizes that these supportive/ancillary services are needed, in addition to essential quality medical care, to ensure positive birth outcomes and the maintenance of good health for women, children, youth, and families among this high-risk population. MDPH provides funding for services not currently or fully reimbursed by other mechanisms including: outreach and case finding, service coordination, social services, nutrition services, and health education in order to augment perinatal and pediatric medical services. For further information, contact the Bureau of Family and Community Health at (617) 624-6060.

### **Special Supplemental Nutrition Program for Women, Infants and Children Program (WIC)**

WIC contributes to reduced infant mortality and morbidity, improved participant health outcomes, and savings in health care costs. WIC participants receive nutrition education, as well as, vouchers for nutritious foods, such as milk, cheese, fruit juices, iron-fortified cereals, peanut butter, dried beans and eggs. The WIC Program collaborates with the Department of Food and Agriculture to provide WIC participants with coupons, redeemable at Farmers' Markets for fresh fruits and vegetables. WIC also collects and reviews the immunization status of its infants and children and makes referrals to keep children up to date on their shots. For more information about participating in WIC: (800) 942-1007 or check the web site

at <http://www.state.ma.us/dph/wic.htm>.

### **Substance Abuse Services**

The Massachusetts Department of Public Health, Bureau of Substance Abuse Services, works to ensure the delivery of the highest quality, culturally-competent, cost-effective array of alcohol and other drug prevention, treatment, and recovery services to individuals, families and communities in Massachusetts. The Bureau offers a range of programs that ensures services to people with disabilities including prevention services, intervention services, acute treatment, transitional services, residential treatment, ambulatory services and supportive housing. For more information, please call the Massachusetts Substance Abuse Information and Referral Helpline at (800)-327-5050. The web site is located at <http://www.state.ma.us/dph/bsas/bsas.htm>.

### **Tobacco Control Program**

The Massachusetts Tobacco Control Program (MTCP) funds a comprehensive network of statewide, regional and community-based tobacco control services and activities that promote smoking prevention and intervention designed to prevent young people from using tobacco products, persuade smokers to stop smoking, and reduce exposure to environmental tobacco smoke (ETS). MTCP offers interventions and referrals within many private and publicly funded programs that touch women of childbearing age, children and adolescents including the WIC program, the Perinatal Tobacco Cessation Program and primary care programs, the Children's Medical Security Plan, Healthy Start, family planning, adolescent health, school based health centers and enhanced school health services. Contact a [cessation program](#) in your area, or to call the Smoker's Quitline (1-800-TRY-TO-QUIT). The web site is located at <http://www.state.ma.us/dph/mtcp/home.htm>. For materials, contact the Massachusetts Tobacco Education Clearinghouse at (617) 482-9485 or check the web site at <http://www.jsi.com/health/mtec>.

## SELECTED NATIONAL RESOURCES

### **American Heart Association**

National Center  
7272 Greenville Avenue  
Dallas, Texas 75231  
1-800-AHA-USA1 (1-800-242-8721)  
Local Office  
20 Speen Street  
Framingham, MA 01701  
508-620-1700  
or 1-800-662-1701  
Fax: 508-620-6157  
[www.americanheart.org/children](http://www.americanheart.org/children).

### **American Academy of Pediatrics**

141 Northwest Point Boulevard  
Elk Grove Village, IL 60007-1098  
847/434-4000  
847/434-8000 (Fax)  
[www.aap.org](http://www.aap.org)

### **Centers for Disease Control**

1600 Clifton Road  
Atlanta, GA 30333  
(404) 639-3534  
(800) 311-3435  
<http://www.cdc.gov>

### **Cleft Palate Foundation**

104 South Estes Drive, Suite 204



Chapel Hill NC 27514  
(800) 24-CLEFT  
<http://www.cleft.com>

**Family Voices National Office**

Post Office Box 769  
Algodones, New Mexico 87001  
1-888-835-5669 (toll-free)  
505-867-2368  
505-867-6517 (fax)  
E-mail: [kidshealth@familyvoices.org](mailto:kidshealth@familyvoices.org)

**Federation for Children with Special Needs**

Parent referral, special education, and legal rights training.  
1135 Tremont Street, Suite 420  
Boston, MA 02120  
(617) 236-7210 (800) 331-0688 (in MA)  
<http://www.fcsn.org/>

**Genesis Fund**

1 Randolph St.  
Canton, MA 02021  
(781) 575-1177  
fax : (781) 575-1260  
[www.thegenesisfund.org](http://www.thegenesisfund.org)

**Helping Hands Foundation**

45 Ledgetree Road  
Medfield, MA 02052  
[eastco@mdc.net](mailto:eastco@mdc.net)  
(For children with a unilateral limb defect)

**March of Dimes**

1275 Mamaroneck Ave  
White Plains, NY 10605  
1-888-663-4637  
Massachusetts Chapter  
One Edgewater Dr.  
Norwood, MA. 02060  
(781)762-4747  
<http://www.modimes.org>

**National Association for Down Syndrome**

P.O. Box 4542  
Oak Brook, IL 60522  
<http://www.nads.org>

**National Birth Defects Prevention Network**

<http://www.nbdpn.org/NBDPN/>

**National Institute of Health**

Bethesda, Maryland 20892  
<http://www.nih.gov/>

**National Organization for Rare Disorders, Inc.**

P.O. Box 8923  
New Fairfield, CT 06812-8923  
<http://www.rarediseases.org/>

**Prescription Parents, Inc.**

Parents helping parents of children with cleft lip & palate  
22 Ingersoll Road

Wellesley, MA 02181  
(781) 431-1398  
<http://www.samizdat.com/pp1.html>

**Spina Bifida Association**  
4590 Mac Arthur Blvd., NW, Suite 250  
Washington, DC 20007-4226  
(800) 621-3141 or (202) 944-3285  
<http://www.sbaa.org/>